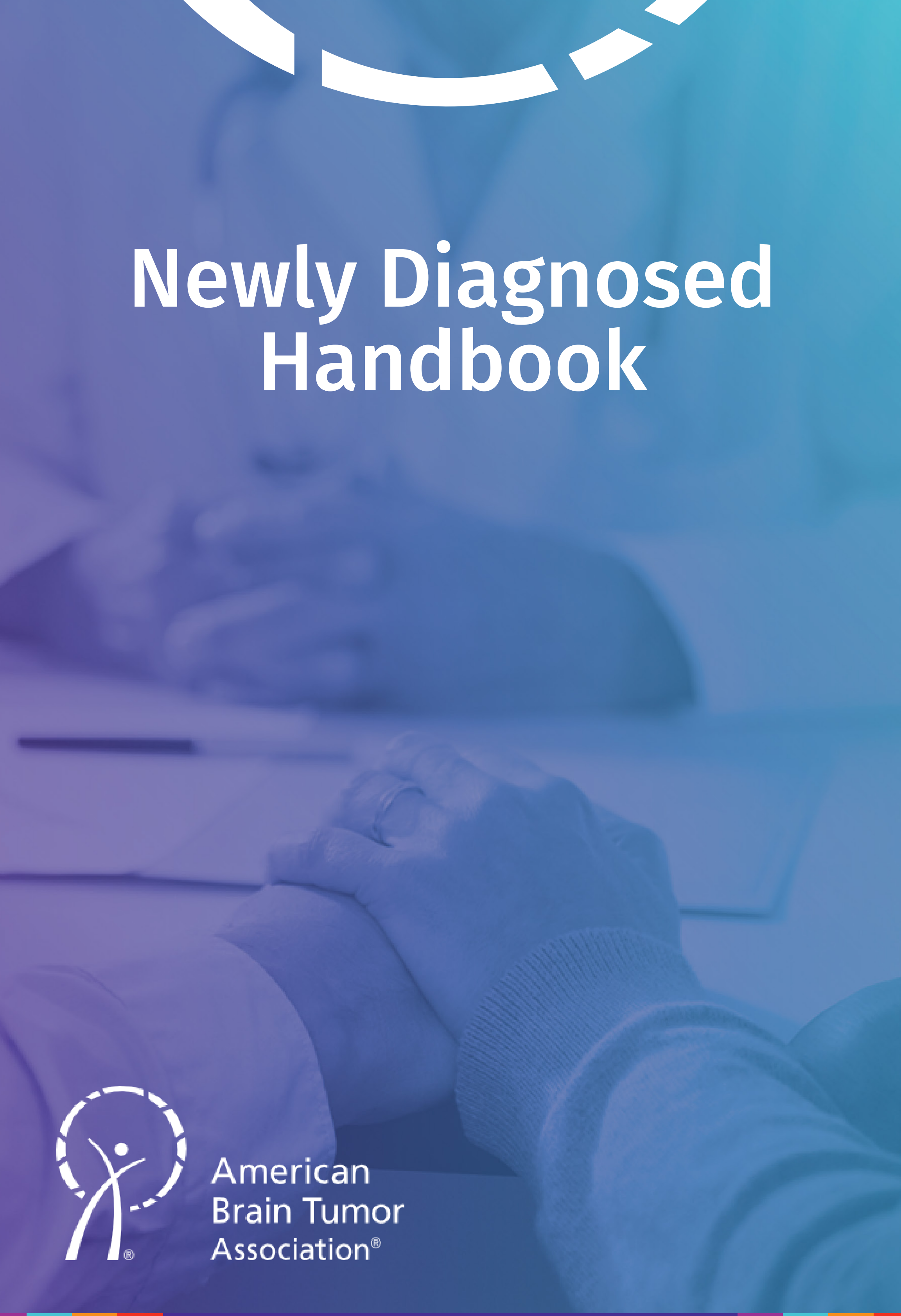


Newly Diagnosed Handbook

American Brain Tumor Association®

Acknowledgements

About the American Brain Tumor Association

Founded in 1973, the American Brain Tumor Association (ABTA) was the first national nonprofit organization dedicated solely to brain tumor research. The ABTA has since expanded our mission and now provides comprehensive resources to support the complex needs of brain tumor patients and caregivers, across all ages and tumor types, as well as the critical funding of research in the pursuit of breakthroughs in brain tumor diagnoses, treatments, and care.

To learn more, visit abta.org.

The ABTA gratefully acknowledges the following for their review of this brochure edition: Carlen A. Yuen, MD (Neuro-oncology, University of California, Irvine), Toni Cao (Northwestern Memorial Hospital), and Tom Rogers.

ABTA0325

The ABTA is Here for You

Nobody expects to hear "It's a brain tumor." When you do, anything else you hear likely doesn't make sense. To say it's a life-changing diagnosis doesn't begin to cover all the ways it may impact your life physically and emotionally. But you do not have to face it alone. Whether diagnosed with a primary or metastatic brain tumor, as an adult (ages 40+), adolescent or young adult (ages 15-39), or as a child (ages 0-14), the ABTA is here to help you through every step of your brain tumor journey.

This handbook was written to empower you, your family, and your friends to take an active role in your treatment and care decisions. The different sections of the handbook focus on:

- Diagnosis
- Second Opinions
- Insurance and Financial Assistance
- Quality of Life
- About Brain Tumors
- Questions to Ask Your Doctor

The information and suggestions offered come from experts and individuals who have been diagnosed with a brain tumor, along with their family members. The ABTA can provide additional information about your specific type of tumor, the treatment options you've been given, and resources for more information and support.

No matter where you are on your journey, one of the important resources the ABTA offers is just a phone call away.

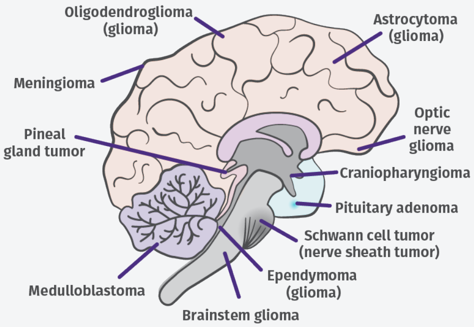
The **ABTA CareLine** staff are trained to help you,
or your loved one, navigate questions you may have.
Simply call **800-886-ABTA (2282)** or email **info@abta.org**.

The Diagnosis

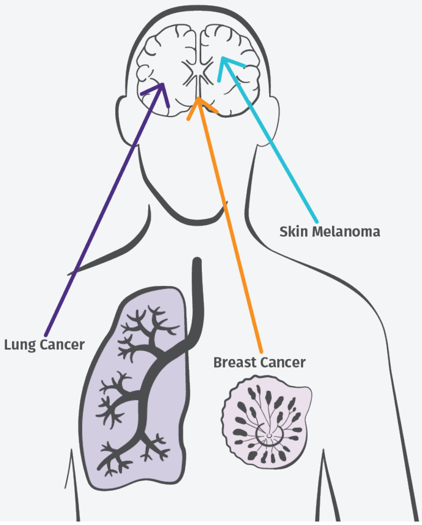
You've just been told that you have a brain tumor. Depending on your situation, you may need additional tests to identify the tumor and its location, immediate surgery, more time to review treatment options, or no treatment at this time with a follow-up in a few months. Many brain tumors can be successfully treated or even cured.

You may be wondering if you did anything to cause your brain tumor. The long and short answer is "No." Even the medical community does not know why some people get brain tumors and others do not. Risk factors that may raise a person's chance of developing a primary brain tumor are exposure to high levels of ionizing radiation and rare genetic disorders.[2] There are also some primary cancers such as breast cancer, lung cancer or melanoma, which have a higher risk of going to the brain and forming a brain tumor.

PRIMARY BRAIN TUMORS



METASTATIC BRAIN TUMORS



There are two categories of brain tumors: primary and metastatic.

Primary brain tumors are also known as **central nervous system (CNS)** tumors because they begin in the brain or spinal cord. If it is a primary brain tumor, that means it started in the brain or spinal cord and is unlikely to spread to other parts of the body.[1] Primary brain tumors can be benign (not cancerous) or malignant (cancerous). Even if your brain tumor is benign, which about 70% of primary brain tumors are,[2] it can still be a serious medical condition and may require treatment with or without surgery.

If the tumor is a **metastatic brain tumor** that means it has spread from another part of the body, such as the lungs.[1,5] *To learn more about metastatic brain tumors, read the ABTA's Metastatic Brain Tumor brochure.*

Whether you or your loved one has been diagnosed with a brain tumor, there is a lot you will need to learn to help navigate your next steps. The information that follows provides an overview of diagnostic tests and treatment options. Remember, every tumor is unique, and you and your healthcare team will select the appropriate diagnostic tests and treatments based on the tumor type and other considerations.

Symptoms and Side Effects

Symptoms refer to the emotional, cognitive, or physical changes that are caused by the brain tumor. Each person will experience unique or different symptoms, depending on the location and size of the brain tumor.[1] Side effects are the emotional, cognitive, or physical changes caused by treatment(s) for the tumor. Treatments that can potentially cause side effects include surgery, chemotherapy, radiation therapy, targeted therapy, medical devices, and other medications. Once you begin treatment, knowing the difference between symptoms and side effects can be challenging.

Common emotional symptoms/side effects include personality, mood, or behavior changes.[1,2] A person may experience extreme personality changes, going from being a quiet and calm person to a loud and aggressive one. One may have mood swings or sudden outbursts. A person may have problems coping with their diagnosis by showing signs of sadness, worry, and/or depression. One may even become delusional, believing things that aren't true, or may experience hallucinations - hearing, seeing, or smelling something that isn't there.

Cognitive symptoms/side effects are related to thinking, learning, concentrating, remembering, problem-solving, and decision-making.[1] A person may have problems talking, reading, understanding, and/or following simple directions. A person may also be confused and have memory loss.[10]

Common physical symptoms/side effects caused by a brain tumor include headaches, seizures, fatigue, nausea and vomiting, loss of appetite, and muscle weakness.[1,2] A person may have headaches that are often worse in the morning and may occur with nausea and vomiting.[7] One may suddenly have seizures without any underlying cause.[9] When fatigued, a person may be very sleepy no matter how much sleep they get or lose interest in doing any activities.[1,2,7] One may have blurred vision, double vision, or loss of peripheral or side vision or hearing problems.[1,8] One may also have trouble standing or walking properly or maintaining a sense of balance.[1,8]

More information about symptoms and side effects can be found at ***abta.org****.*

Diagnostic Tests

Doctors use different types of tests to find and diagnose a brain tumor. These tests help them to learn what type of tumor it is, as well as its size and location. These tests are often done by different specialists and providers who are part of your healthcare team.

The diagnosis begins with a thorough medical history and physical examination.[1,7] The doctor will do a series of neurological exams to test your brain and spinal cord function. These include testing how well your reflexes, muscles, and senses work and your cognitive skills, such as awareness, attention, memory, and judgment.

The doctor may order one or more imaging tests that create detailed pictures of the brain. These images can detect a tumor's location, size, and other features.

A **magnetic resonance imaging (MRI) scan** is the preferred imaging test for evaluating brain tumors because it is better than other imaging tests at identifying important features.[2] In certain cases, the doctor may want to do a specialized MRI, such as a magnetic resonance spectrometry or functional MRI.[2] Patients with a pacemaker or other implanted medical devices, or those who are overweight or fear being in enclosed spaces may require special accommodations to obtain a MRI or may not be able to obtain a MRI. Those patients will be scheduled for a computed tomography (CT) scan, which is also very helpful in identifying the presence of a tumor.[2,14] These imaging tests are usually done with contrast, which is a dye that makes the scanned images clearer.[1,13] An additional imaging test that looks at the whole body — **a positron emission tomography (PET) scan** — may be ordered to help distinguish a primary tumor from a metastatic one if needed.[1,]

Although imaging tests provide clues to a brain tumor diagnosis, a biopsy or surgical resection is needed to be sure of the diagnosis.[2,14] During a biopsy, the neurosurgeon surgically removes a small piece of the tumor tissue and sends the sample for testing to a pathologist. If the tumor is in a location that is hard to reach or the patient is not healthy enough to have open surgery, the neurosurgeon may do a stereotactic biopsy, which uses a computer and a three-dimensional scanning device to help guide the removal of tissue.[1] The neurosurgeon may decide to do a surgical resection to remove as much of the tumor as they can safely.[15] In that way, a surgical resection serves as both a diagnosis and treatment, as removing as much of the tumor as possible could relieve symptoms.

Doctors use molecular testing to diagnose brain tumors because it can check for changes, sometimes called biomarkers, in a chromosome, gene or protein that can help diagnose a brain tumor. A biomarker is a gene, protein, or other molecule found in blood, urine, or tissue that may be a sign of an underlying condition or disease.[20] Finding changes in the tumor can help doctors understand the tumor better and determine the best treatment options for you. Doctors will use the molecular testing results, as well as histology (how the cells look under the microscope) to determine an accurate diagnosis and, ultimately, a treatment decision.

Brain Tumor Grades

Unlike other cancers, the World Health Organization (WHO) uses a grading system with a scale of 1 to 4 for primary brain tumors rather than a staging system because they rarely travel to other parts of the body. A tumor grade tells how normal or abnormal the tumor cells look when viewed under a microscope.[1,9] Based on the WHO's grading system, the higher the grade, the less normal the cells look and the quicker the tumor grows.[21]

In the past, the diagnosis of brain tumors relied more heavily on their grades. While that information is still important, it is more common today to include molecular testing results to help diagnose a brain tumor.[20,21] The **neuropathologist,** a doctor who studies brain tumor tissue removed during surgery, will examine the tumor tissue under a microscope to determine the tumor type and grade. The neuropathologist will also use the tissue sample to do molecular testing or possibly send the tissue to companies that specialize in detailed molecular testing.

WHO Tumor Grading System

> *Grade I*

The tumor cells look almost normal under a microscope. They tend to grow slowly and rarely spread. Grade 1 brain tumors may require only surgery. These are also known as benign tumors.

> *Grade II*

The tumor cells look somewhat abnormal under a microscope. They tend to grow slowly but may spread to nearby tissue. Grade 2 brain tumors may need additional treatment after surgery. Following treatment, they may return as a higher-grade tumor. These tumors may be either benign or malignant (cancer).

> *Grade III*

The tumor cells look abnormal under a microscope. They tend to grow quickly and are likely to spread to nearby tissue. Grade 3 brain tumors often require radiation or chemotherapy after surgery. These tumors are considered to be cancer, or malignant.

> *Grade IV*

The tumor cells look very abnormal under a microscope. They grow and spread very quickly. There may be areas of dead cells in the tumor. Grade 4 tumors usually cannot be completely removed by surgery and require radiation, chemotherapy, or both after surgery. These tumors are considered to be cancer, or malignant.[1,9]

The neuropathologist will relay all this information to your doctor in the pathology report. Based on the findings, your doctor will recommend the best treatment options for the type and grade of brain tumor you have. This information will also help determine your **prognosis** (the chance of recovery or survival from a disease).

Tumor stage (stage I-IV) tells how large the tumor is and whether the tumor cells have traveled to other parts of the body. We do not use the tumor stage to classify brain tumors; however, it is used with cancers that begin elsewhere in the body (lung, breast, etc.) and have spread to other areas of the body, known as stage IV metastatic cancer.

Fertility Preservation

Some treatments, including surgery, for a brain tumor may affect the ability to have children. Talk to your doctor and healthcare team to know how your treatment options may affect fertility before starting treatment. If you are of reproductive age, ask for a referral to speak with a reproductive specialist who can explain what options for preserving your fertility are available.[26] Fertility preservation requires a multidisciplinary approach. Don't assume your doctor will ask about your fertility concerns. You might need to start the conversation.

Both the American Society of Clinical Oncology and the American Society of Reproductive Medicine recommend that every patient of reproductive age diagnosed with a brain tumor that will require anti-cancer treatment be seen by a reproductive specialist.[26]

Treatments

Active Surveillance

Active surveillance is a watch and wait approach that involves closely monitoring a brain tumor.[1] The patient will have routine exams and tests to monitor the tumor. This approach may be used for slow-growing tumors that are not causing any symptoms.

Surgery

Surgery remains the first step in the treatment of many brain tumors.[9] The doctor who specializes in brain surgery is called a neurosurgeon. The goals of surgery are generally to get a tissue sample to make a diagnosis (if a biopsy was not already done), remove as much tumor as possible, and reduce symptoms caused by the tumor while preserving the patient's ability to function.[13,18] Just as there are different types of brain tumors, there are different surgical approaches that can be used to treat them. Surgery may be the only treatment needed for a benign or low-grade brain tumor. To learn more, read the ABTA's Surgery brochure.

Radiation Therapy

Radiation therapy is recommended to slow or stop a brain tumor from growing. The doctor who specializes in radiation therapy is called a radiation oncologist. Using high-energy, very focused rays, radiation therapy will be given to kill tiny pieces of tumor that remain following surgery or to kill tumor cells for a tumor that cannot be surgically removed.[13,18,29] Stereotactic radiosurgery is an advanced form of radiation therapy that uses either photon or proton beams to deliver high-dose radiation to within one millimeter of the target. Their precision helps minimize the negative impact to surrounding healthy tissue and organs beyond the tumor, which may result in fewer side effects of the treatment itself. Tiles that help direct radiation to the tumor site are also an option and are placed during surgery.[13] Children younger than three years of age are usually not given radiation because of possible long-term side effects with brain development. Instead, they are treated with surgery and chemotherapy. Radiation can also cause some problems in older children. To learn more, read the ABTA's Conventional Radiation Therapy and Stereotactic Radiosurgery brochures.

Chemotherapy

The doctor who specializes in chemotherapy for brain tumors is called a neuro-oncologist. Chemotherapy uses medications to stop or slow the growth of cancer cells.[1,13] It can be given as one drug alone or a combination of drugs. Chemotherapy can consist of oral pills, an intravenous (IV) infusion, an intrathecal infusion into the cerebrospinal fluid, injected into a vein or muscle, or given as a wafer implanted during surgery.[1,34] How chemotherapy is given will depend on the type, grade, and location of the brain tumor.[1] It is often used as part of a treatment plan that includes surgery and/or radiation therapy.[9] Chemotherapy is often given in cycles, allowing patients time for recovery between treatment.[14] Chemotherapy can be given before surgery (neoadjuvant chemotherapy), at the same time as radiation (concurrent chemotherapy), or after surgery/radiation (adjuvant chemotherapy). Temozolomide (also known as TMZ) is an oral chemotherapy drug that has been approved by the Food and Drug Administration (FDA) to treat glioblastoma. To learn more, read the ABTA's Chemotherapy brochure.

Tumor Treating Fields

Tumor treating fields is a treatment that has been approved by the U.S. Food and Drug Administration (FDA) for the treatment of glioblastoma.[15] It involves wearing what resembles a swim cap connected to a portable, battery-operated device that creates low-intensity electric fields that interfere with the tumor cells' ability to grow and divide.[13] The device is recommended to be worn for at least 18 hours a day to get the best response.

Targeted Therapies.

Targeted therapies use drugs to target proteins in the tumor that control how tumor cells grow, divide, and spread. Targeted therapies use different mechanisms than traditional chemotherapies. The drugs attack the tumor cells, stopping them from growing or spreading. Targeted therapies are delivered by IV/infusion or orally (pill). Currently, there are only a few targeted therapies approved for treating brain tumors. Bevacizumab is a monoclonal antibody that has been approved by the FDA to treat recurrent glioblastoma. Vorasidenib was recently approved by the FDA for the treatment of IDH1/2 mutant Grade 2 gliomas. The doctor can run molecular tests to identify which proteins the tumor is made of to choose the best targeted therapy for each patient.

Immunotherapies

Immunotherapies use drugs to enlist the body's own immune system to fight a brain tumor. Some types of immunotherapies only target certain cells of the immune system, whereas others affect the immune system in a general way. Immunotherapies are being studied as possible treatment options for glioblastoma and other brain tumors.

Image is being used with permission from Novocure GmbH.

Clinical Trials

Clinical trials are experimental research studies that test how safe and effective potential new treatments or approaches are.[1] Participating in a clinical trial is a way to gain access to new drugs, devices, or treatments that are yet to be approved by the FDA. A clinical trial may be a good option, depending on your brain tumor type. Discuss this option with your doctor early on because some clinical trials aim to treat before undergoing surgery (also called neoadjuvant therapy), while others may first require the tumor to be removed. It's also important to discuss this option with your doctor early on because some clinical trials require tumor tissue to participate in the clinical trial. The ABTA can help you find a clinical trial.

To learn more, read the ABTA's Clinical Trials brochure

Palliative Care

Brain tumors and their treatments cause physical symptoms and side effects. Relieving these symptoms and side effects is an important part of **supportive care,** sometimes referred to as **palliative care**. Palliative care is for anyone, regardless of their age, or type and stage of disease. Palliative care can be used at the time of diagnosis, throughout treatment and recovery, and during end-of-life care. **People who receive palliative care often have less severe symptoms, better quality of life, and are more satisfied with treatment**. More information about palliative care can be found later in this booklet.

Monitoring for Recurrence

Brain tumors can recur (come back). This usually happens after a period of time during which the tumor could not be detected or when residual tumor, which could not be fully removed, grows again after treatment. A tumor may come back in the same place as the original (primary) tumor, or it can occur in another place in the central nervous system.[1,47] This is also called recurrence. Some types of brain tumors can return or spread into additional tumors. Glioblastoma and medulloblastoma often recur, however all types of brain tumors can recur. Metastatic brain tumors can present as one tumor or multiple tumors. That is why follow-up care is so important. Even after treatment has ended, patients should have regularly scheduled physical and neurological exams, blood tests, and imaging tests.[46,47] Treatment for a recurring brain tumor may include surgery, radiation, chemotherapy, a clinical trial, surveillance, and/or supportive care.[46]

Prognosis

A prognosis is based on statistics that look at a large group of people with the same disease over time. Statistics on survival rates are only estimates and cannot be used to predict what exactly will happen to you. Among the factors that can affect prognosis are tumor grade, type, and location; extent of spread; amount of tumor remaining after surgery; age; overall health; and molecular findings.[45]

Next Steps

While processing a brain tumor diagnosis, you will need to make some treatment decisions. In some cases, those decisions will need to be made quickly. In others, you may have more time to consider your options. Either way, there are some things you should consider that may influence your choices. Some of the following considerations may help you to make more informed decisions about a treatment or care plan with the help of your doctor and healthcare team.

Getting a Second Opinion at a Brain Tumor Treatment Center

Since brain tumors are considered a rare disease, a second opinion from someone who treats a lot of brain tumors is critical in evaluating your treatment and care options. If you need emergency surgery, you may need to wait until after the surgery to get a second opinion. If you don't need emergency surgery, it is recommended to get a second opinion before your surgery. You can get a second opinion at any time. Getting a second opinion from another doctor or multidisciplinary team of specialists can help you choose a care plan that works best for you.

The ABTA strongly encourages everyone to seek a second opinion from a brain tumor specialist at a brain tumor treatment center *before* starting any treatment.

Don't worry that seeking a second opinion will offend your doctor. It's expected by doctors, especially when faced with such a serious diagnosis as a brain tumor. Many times, doctors suggest seeking a second opinion. Most of them welcome a colleague's opinion and may even provide you with a recommendation. The goal for everyone is for you to have the best care possible.

It's important to understand the difference between community hospitals and medical institutions with a dedicated brain tumor treatment program. Community hospitals tend to provide short-term general care for patients, and some may focus on a specialty, such as orthopedics. In contrast, medical centers with a dedicated brain tumor program have access to brain tumor specialists and clinicians who have knowledge of the latest brain tumor research findings, which informs their clinical decision making, the latest brain tumor research findings, and newer treatment technologies. Most brain tumor centers also have access to clinical trials for new potential therapies.

For children, pediatric medical or cancer institutes are best equipped to navigate a brain tumor diagnosis.

If diagnosed with a metastatic brain tumor, you or your loved one may already have a dedicated healthcare team associated with a cancer treatment center who can refer you to a neuro-oncologist, or you can choose to explore different brain tumor treatment centers.

To help make your search easier, the ABTA website offers a list of **Brain Tumor Treatment Centers** that allows you to search for brain tumor treatment centers for adults and children by institution or hospital name, state, or zip code. You can search this resource to find out how many brain tumor patients the center treats, how many neuro-oncologists and radiation oncologists are on staff, and if they offer clinical trials or other specialized treatments. Getting a second opinion doesn't mean you have to go with it. If nothing else, a second opinion can provide you with peace of mind.

Before, During and After a Second Opinion

To prepare for a second opinion, gather all your medical records from the time of diagnosis. A new doctor will need to review these records. They should include all imaging tests, pathology report, blood work, operative and consultation reports, office visit records, and any other testing that may have been done. You can request these records from your doctor's office or the hospital's medical records department, and they can be delivered directly to you or the new doctor. There may be a charge for getting a copy of your records.

After reviewing your medical records, the new doctor may need to do more tests or scans to provide their diagnosis and treatment recommendations.

The new doctor may have the same recommendation as your original doctor or the new doctor may recommend something different. If both doctors offer the same recommendations, you can return to your original doctor or choose to get treatment from the new doctor. If the opinions differ, you can return to the first doctor to discuss the second opinion. Talk about the differences. Talk about your concerns. You could ask the two doctors to review your case together, allowing them to explain how they arrived at their recommended treatment plan. You could have a brain tumor board review your case as a third opinion, or you could seek a third opinion from another doctor. The ABTA would not advise getting more than three opinions.

Ultimately, you are your best advocate. Weigh the potential benefits of each treatment plan, think about which care plan feels right for you, consider your doctor's recommendations, consider your relationship with your doctor, and choose the best option for you. Not every option works for every patient.
In the end, it's your choice. No matter what route you go, your doctor and healthcare team should honor your decision. Some questions you may want to ask are included in section 5 of this booklet.

Finding Out About Insurance Coverage

If you have health insurance, you will need to work with your insurance provider. This can be difficult because insurance can often be complex and confusing. A hospital's social worker, case manager, or nurse navigator can help you work through it. It is important to review your policy, especially what it says about in-network providers, deductibles (the amount you pay for covered healthcare services before your insurance plan starts to pay), pre-authorizations (decisions made by the plan that a healthcare service, treatment plan, or prescription drug is medically necessary), the list of medications covered on its formulary, and any limitations to your coverage.

If you choose a doctor who practices outside of your area, ask if your insurance covers virtual visits. Many insurance companies pay for telemedicine visits. Find out if there are limitations to the services covered and whether you will have to pay a co-pay, similar to in-person doctor's visits.

Before calling your insurance provider, review your policy and note any questions or concerns you have about coverage.

If you don't have insurance, contact the hospital's social worker, case manager, or nurse navigator. They can outline insurance options, federal assistance programs, local and national funding organizations, and other ways to help you find alternative forms of healthcare coverage.

Some questions you may want to ask are included in section 5 of this booklet.

Learning About Financial Assistance

Being diagnosed with a brain tumor can cause financial hardship, but there are financial assistance programs available to ease the burden. Some programs offer financial aid for services such as travel expenses and housing costs, out-of-pocket costs related to insurance coverage, and medications. Others help pay for household expenses such as rent or mortgage, utilities, and groceries.

To learn more, speak with your medical institution's social worker about local resources, contact the ABTA CareLine at 800-886-2282 or visit abta.org to learn about the ABTA Financial Assistance Program, Glenn Garcelon Fund, and other resources. Visit the Financial Assistance section of the ABTA's website to learn about financial assistance programs for children, adolescents, and adults impacted by a brain tumor diagnosis.

Quality of Life

Managing your quality of life during and after treatment for a brain tumor is as important as treating the tumor itself. Many people who live with a brain tumor or who are undergoing treatment experience significant changes in the way they function, feel, or think.

When physical, emotional, or cognitive changes are caused by the brain tumor, they are considered *symptoms*. When they are caused by treatment(s) for the tumor, they are called *side effects*. Among the treatments that can potentially cause side effects are surgery, chemotherapy, radiation therapy, immunotherapy, tumor-treating fields, and various medications. Sometimes it is hard to know the difference between symptoms and side effects.

Getting supportive care, sometimes referred to as **palliative care**, to relieve both symptoms and side effects is key to managing your quality of life. Palliative care is often confused with hospice care, which is support for end-of-life care, but it covers much more than hospice care. Palliative care is for anyone, no matter what their age or tumor type. It may include medications, relaxation techniques, nutritional changes, exercise, pain management, and emotional and spiritual support.

It may be most beneficial to start supportive care shortly after your diagnosis, but you can begin it at any time during treatment and even after treatment is finished. People who receive palliative care often have less severe symptoms, better quality of life, and are more satisfied with their treatment.

You should talk to your healthcare team about the specific symptoms/side effects that you are experiencing. Speaking with your healthcare team regularly about how you feel emotionally and physically will help them find ways to relieve or manage your symptoms/side effects to help you feel more comfortable and possibly keep them from getting worse.

Some medical centers have a palliative care team to help you manage and treat symptoms/side effects. The palliative care team may include physicians, nurses, physical and occupational therapists, registered dietitians/nutritionists, psychiatrists, psychologists, counselors, social workers, and chaplains. Depending on your specific symptoms/side effects, you may work with one or a few of them. If your medical center does not have a palliative care team, your doctor can refer you to providers like those who serve on a palliative care team.

The symptoms you experience often depend on the location of the brain tumor. That's because different parts of the brain, often referred to as *lobes*, control different functions,[2] such as thought and reasoning versus vision and hearing. A brain tumor located in one of these lobes could affect how your brain signals your body to act. But because areas of the brain connect to each other, it is possible that the tumor could impact a function of the brain where the tumor is not located.

Managing Your Mental Health & Emotional Symptoms/Side Effects

Brain tumors in the frontal lobe may cause emotional symptoms/side effects, such as personality, mood, or behavior changes.[8,11]

Personality changes and mood swings can be challenging to deal with for both you and your loved ones. You may change from being a driven person to lacking energy and motivation. Mood swings may cause you to switch from feeling calm to agitated or kind to rude. You may become depressed, as many patients with brain tumors experience depression. If left untreated, depression could slow your recovery.

In addition, you may be stressed and anxious about your diagnosis; patients learning that they have a brain tumor commonly are. A racing heartbeat, loss of appetite, sleep disturbances, and intense worry are all signs of anxiety. If you or your loved one is experiencing any of these symptoms, it's important to get help.

It is widely believed that high levels of stress, especially when they continue for a long period of time, have a negative impact on one's physical and mental health. Relaxation techniques can help lower stress and cope with anxiety.[51] They may include relaxed or deep breathing, mental imagery or visualization, progressive muscle relaxation, meditation, mindfulness, biofeedback, acupuncture, and yoga. You can learn most of these techniques in a few sessions with a counselor or through self-help resources. Many medical centers have integrative health classes to teach patients relaxation techniques. Consider using these techniques daily or at stressful times, such as during a diagnostic procedure or treatment, or when receiving test results. Palliative care can include complementary therapies, such as art or music, which engage your mind, and in some cases, your body. Engaging in new and challenging activities such as these can give you a sense of accomplishment and serve as a distraction from everyday worries. Talk to your nurse navigator or social worker about what types of classes are available near you.

Talk to your doctor about getting a neuropsychological evaluation. During this evaluation, a neuropsychologist will assess different brain functions and mood and behavior changes and then recommend how to treat your specific symptoms/side effects. Counseling and/or psychotherapy, lifestyle changes, and psychiatric medications can help reduce emotional symptoms/side effects.

A mental health provider may suggest counseling, which can help you adjust to your diagnosis, address grief, and manage stress. Counseling can help alleviate mood swings and depression, as well. Cognitive behavioral therapy, which focuses on changing thoughts and actions, can help with depression, anxiety, pain, and fatigue. Learning strategies, such as positive reinforcement, can help change problem behaviors. Psychotherapy can help address a broader range of mental health needs. It has been shown to reduce anxiety and depression while increasing spirituality in patients with brain tumors. Medications, such as antidepressants and anxiolytics, may be used to treat depression and anxiety.

Managing Your Physical Symptoms/Side Effects

Common physical symptoms caused by a brain tumor include headaches, seizures, fatigue, nausea and vomiting, loss of appetite, and muscle weakness.[1,2]

Headaches are caused by the tumor or related swelling (edema) which builds pressure in the brain. Your doctor can prescribe medication to treat your headaches. Over-the-counter pain relievers or prescribed narcotics may help with the pain, while steroids can reduce the swelling in the brain caused by the brain tumor. If the medication stops working or becomes less effective, tell your doctor. Keeping a *headache journal* may help your doctor treat your headaches more effectively.

Seizures are sudden, uncontrolled body movements and changes in behavior that occur because of abnormal electrical activity in the brain. Symptoms can include loss of awareness, changes in emotion, loss of muscle control, tongue biting, loss of bladder control, and shaking.[57] Seizures can be managed with anti-epileptic drugs. It's important to take this medication as prescribed because a steady level is needed to be effective. Surgery to remove the tumor may also stop or reduce seizure activity. Basic guidelines for handling a seizure include staying with the patient, calling 911, and not putting anything in their mouth. To learn more about how to handle seizures, view the **ABTA webinar** on seizures, found on the ABTA's YouTube channel, and download the **Seizure First Aid Flyer**, available for download on the ABTA's website.

Fatigue can range from a lack of energy, motivation, or interest in daily activities to a sudden sense of tiredness or a strong need to rest.[1,2] Symptoms of fatigue may be improved by adjusting your lifestyle, eating to increase your energy, and exercising to boost your energy levels. Depending on your specific symptoms, your doctor can prescribe certain medications to alleviate fatigue.

Your doctor may prescribe medication to control **nausea and vomiting**. Remarkable advances have been made in the development of a new generation of drugs called *antiemetics* to help offset these side effects. Prior to starting treatment, ask your healthcare team if any of your treatments, like chemotherapy, will cause nausea or vomiting. If so, be sure you are provided with an "antiemetic plan" specific to the drugs you will be given. Antiemetics can be both preventive drugs that can help control nausea and vomiting before it starts or to use if you are already nauseated or actively vomiting. In addition, eating a healthy diet may help alleviate nausea, vomiting, and loss of appetite.

If you are experiencing **muscle weakness**, ask your doctor for a referral to a physical therapist or occupational therapist. Physical therapy can help address muscle weakness by improving your physical strength, coordination, balance, and mobility. Occupational therapy can help you regain the ability to perform daily tasks, such as feeding yourself or getting dressed. Occupational therapists can also help with more difficult skills, such as shopping, preparing meals, or taking transportation.

Managing Your Cognitive Symptoms/Side Effects

Cognitive symptoms are related to thinking, learning, concentrating, remembering, problem-solving, and decision-making. Brain tumors may cause problems with memory, speech, hearing, and vision.[10,11] Radiation can also induce cognitive impairment, including decreased verbal memory, spatial memory, attentiveness, and problem-solving abilities.[13] You may have trouble doing any number of these skills.[10]

Neuropsychological testing can help identify cognitive changes in addition to mood and behavior changes. Cognitive rehabilitation helps people relearn these skills or adapt to their impairments through behavioral strategies and interventions. Speech therapy can address problems with speech, language, talking, and swallowing. A speech therapist will test your current function and create a program to address your specific symptoms.

Staying Strong with Nutrition & Exercise

Adopting a healthy diet and sensible exercise program can help you improve your strength and mobility, reduce fatigue, deal with anxiety and depression, and recover more easily.

Maintain a Healthy Diet

A brain tumor diagnosis can change how you feel about food and eating because it can change the way your body tolerates different foods. During treatment, you may experience:

- Nausea
- Vomiting
- Loss of appetite
- Changes in taste
- Diarrhea
- Constipation

Speak with a nutritionist or registered dietitian who can help you evaluate your current eating habits and create a healthy diet plan to meet your nutritional needs before and after treatment. Making a drastic change in your diet is not recommended, but even small changes can have a positive impact on your health.

Keeping a healthy diet means eating foods that offer a balance of proteins, carbohydrates, fluids, healthy fats, and fruits and vegetables. These different food groups help your body in different ways. Proteins help repair your cells, muscles, and immune system, while healthy fats provide energy, absorb vitamins, and protect your organs. Eat a variety of foods from the different food groups that you enjoy.

Certain eating habits and foods can help address symptoms/side effects, including fatigue, loss of appetite, nausea, vomiting, and more. To learn how to address specific brain tumor symptoms/side effects, watch the ABTA's Educational Webinar, **Taking Charge: Caring for Your Mind and Body,** which can be found on the ABTA's YouTube channel. More resources on diet and nutrition, including a **Super Foods Tip Sheet**, are available at abta.org.

Try an Exercise Routine

Research shows that physical activity can improve emotional and mental health symptoms/side effects, including mood, depression, anxiety, and quality of life for some patients with brain tumors. It can also improve physical symptoms/side effects, such as reducing fatigue and building strength. Studies show that exercise improves cognitive symptoms/side effects, including improving the ability to process thoughts, pay attention, concentrate, and remember.[63]

You do not have to adopt a rigorous workout for it to be worthwhile. Walking, swimming, or gardening are all gentle, low-impact exercises that will get your body moving. Many medical centers and cancer support centers offer wellness classes like Tai Chi, Qi Gong, and gentle yoga. If you need lower impact activities, try walking slowly, making the bed, and washing dishes. The goal is to stay active and not spend a large amount of time sitting, lying down, or standing still.

Staying active during and after treatment for a brain tumor can have a lot of benefits. But before starting any physical activity, speak with your healthcare team to make sure that you are well enough to exercise. If you feel up to exercising, your doctor can recommend what type of exercise and how much you can do safely.

Creating a Support System

Navigating a brain tumor diagnosis can be challenging and feel isolating. Having a support system – whether that means family and friends, your healthcare team, or a support group — can help you move forward with your life more easily.

Your treatment center is a great place to start creating a support system. Your nurse navigator, patient navigator, or case manager can explain your treatment plan, what to expect at appointments and from treatment(s) and provide educational materials. For more support, they can refer you to a social worker who can provide counseling and resources or referrals to a mental health provider or chaplain. A chaplain provides support, counseling, and guidance to people with varying degrees of faith or those without faith.

With your support system in place, it is time to share the news about your diagnosis. You are in control of who, when, and how much you share with others.

Share Your Diagnosis with Family and Friends

Sharing news of a brain tumor diagnosis is never easy. But the people who know and love you will want to support you in any way they can. These conversations can be very emotional. Even couples who usually communicate well can have a hard time talking about a life-changing diagnosis, such as a brain tumor. Talk openly and honestly about your thoughts and feelings with your spouse or partner. Share your experience, listen to your spouse, and accept your partner's thoughts and feelings without criticism or blame. Remember that a brain tumor diagnosis will affect both of your lives.

As a parent or guardian, it's natural to want to protect your children from upsetting news. But keeping information from them may make them worry and think the worst is happening. Children often sense when something is wrong. They may overhear conversations or talk with each other. If your child has been diagnosed with a brain tumor, you will want to help them understand their diagnosis. In either case, what and how much you share about the diagnosis with children will depend on their age and what you think they are able to understand. Younger children may not need to know a lot of details, whereas teenagers may want to know more and may need more time to sort through their feelings. Always be clear and reassuring when speaking with children.

A social worker can offer tips on how to discuss brain tumors with family members and may offer counseling for you and family members.[67]

Allow Family and Friends to Help

While you may be used to caring for others, either by earning money, managing the household, or giving emotional support, allowing people to care for you at this time can help you focus on your health and well-being. Nobody expects you to manage your brain tumor diagnosis while managing all your other responsibilities.

Be aware of your limits. If you do not have the time or energy to complete your normal tasks, ask for help—even if it makes you feel a little uncomfortable.

People are likely to offer their support but may not know what exactly they can do. Think about what tasks you may need help with. Giving family and friends something to do will make them feel useful. Be specific about what you want and what you don't want so you will get what you need.

Have a friend or family member drive you to and from appointments or stay with you during treatments, such as chemotherapy, which can take some time, or visit you at home. Having company can be comforting and a good mental distraction. They can help you with daily tasks, such as running errands, cooking meals, or paying bills. You may ask someone to take your children to and from school or activities or provide pet-sitting.

Find Your Brain Tumor Community

While friends and family can offer a tremendous amount of support, it may be helpful to talk with other people going through their own brain tumor journeys. Support groups, either in-person or online, give you a chance to share your feelings with other brain tumor patients, survivors, and caregivers; learn about what they are experiencing; and how they are coping.

Ask your healthcare team to recommend a support group or visit abta.org to find one in your area.

The ABTA also offers a free online support community called **ABTA Connections Support Community**. This online group has nearly 40,000 members of the brain tumor community asking questions and sharing experiences. There are a variety of topics for patients, survivors, and caregivers impacted by a metastatic or primary brain tumor.

If you prefer to connect one-on-one, you can get paired with a mentor through the ABTA's **Patient and Caregiver Mentor Support Program**. This is a free mentor matching service that pairs adult brain tumor patients, survivors, and caregivers with mentors who have been through a similar situation. Connecting with a mentor provides the opportunity to ask personal questions and receive support from someone who is uniquely familiar with the brain tumor experience.

Contact the **ABTA's CareLine** for brain tumor information and resources by calling **800-886-ABTA (2282)** or emailing info@abta.org and a supportive CareLine staff member will be in touch within one to two business days.

Visit the ABTA website section, **Social and Emotional Support**, to find out more about these free programs.

Returning to Work or School

Many people can and do return to work or school after they are diagnosed with a brain tumor. Others may choose to focus on their recovery or spend more time with loved ones. There is no *right* answer. Consider your own needs, capabilities, and preferences and decide what is best for you. Before returning to work or school, check with your doctor and healthcare team to make sure you are healthy enough to make that move.

If you decide to return to work, consider communicating openly with your employer and coworkers. Telling your coworkers about your diagnosis enables them to better support you. Speak with a counselor, social worker, or supervisor to explore the best ways to let your coworkers know and how much to tell them.

The time it takes to recover is different for everyone, depending on tumor type and grade, location, treatment(s), and overall health. Some people may not return to work, while others will through a gradual process. Work with your healthcare team to create realistic timelines that you can discuss with your supervisor. Time is an important part of the process, but it requires patience.

Understand that everyone has limitations, and it is important to know yours. To work around your limitations, figure out what times of the day you have the most energy and schedule your most challenging tasks during that time. If your limitations include disabilities or impairments that limit daily activities, such as short-term memory loss, difficulty walking, or problems with concentration, your employer is required to help you make reasonable accommodations, according to the Americans with Disabilities Act of 1990. This may include job-sharing, flexible hours, and reassignment to a position that is more suited to your abilities, among others.

Students should contact the Office of Services for Students with Disabilities (SSD) at their school. The SSD is there to support students who may have special needs due to medical reasons. The school's SSD office will work with you to determine what accommodations you may need to make your return to classes easier. Such accommodations may include extended deadlines or time allowances for exams, flexible attendance to accommodate appointments and treatments, assigned note-takers, and more.

Visit the ABTA website section of **Living with a Brain Tumor** for more strategies to help you return to work or school successfully.

About Brain Tumors

A brain tumor is a disease in which abnormal cells form in the tissues of the brain and/or spinal cord.[1] According to the World Health Organization, there are approximately 150 different types of brain tumors.

Types of Brain Tumors

The two main types of brain tumors are primary and metastatic.

Primary brain tumors start in the brain. They may spread to other parts of the brain or spine, but they rarely spread to other parts of the body.[1,5] Primary brain tumors can be grouped as benign (non-cancerous) or malignant (cancerous).

Benign Brain Tumors

Benign brain tumors consist of slow-growing cells.[1,23] They usually have defined borders and rarely spread. When viewed under a microscope, their cells appear almost normal looking. However, brain tumors made of benign cells can be in vital areas of the brain, making them life threatening or difficult to treat. Even if your brain tumor is benign — about 70% of primary brain tumors are[2,6] — it may still be a serious medical condition and may require treatment.

Some examples of benign primary brain tumors are meningiomas, acoustic neuromas, and pituitary tumors.

Malignant Brain Tumors

Malignant brain tumors, which are sometimes called *brain cancer,* are usually fast-growing, invasive, and life threatening.[1] When viewed under a microscope, these tumors appear abnormal and lack defined borders. Malignant brain tumors can spread within the brain and spine because they often invade nearby normal tissue. They can also shed cancer cells that travel to far parts of the brain and spine through cerebrospinal fluid, which surrounds the brain and spinal cord.

Malignant primary brain tumors include glioblastomas, diffuse midline gliomas and medulloblastomas.

Benign Tumors	Malignant Tumors
Slow growing	Fast growing
Rarely spread	Tendency to spread
Defined borders	No defined borders
Serious medical condition that could be life threatening	Life threatening

Metastatic Brain Tumors

Metastatic brain tumors begin as cancer elsewhere in the body, such as the lungs, and spread to the brain.[1] Metastatic brain tumors can present as one tumor or multiple tumors in the brain. Also known as *brain metastasis* or a *secondary brain tumor*, a metastatic brain tumor usually spreads through the bloodstream or lymphatic system. The lymphatic system helps the body get rid of toxins, waste, and other unwanted materials and works with the immune system to fight infection.

When a tumor spreads to the brain from another place in the body, it is not called brain cancer. Rather, it is named after the part of the body where the cancer started. Lung cancer that spreads to the brain is called lung cancer brain metastases, breast cancer that spreads to the brain is called breast cancer brain metastasis, and so on.[69] The most common types of metastatic brain tumors are lung cancer, breast cancer, melanoma, kidney cancer, and colon cancer.

The Brain and Nervous System

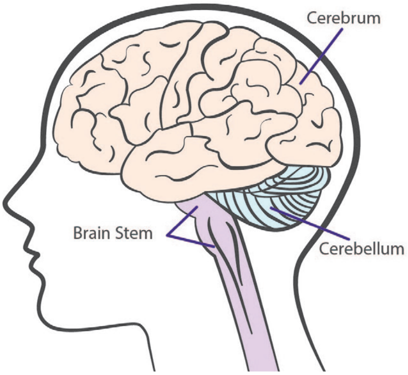
Learning how the brain and spine normally work together may help you better understand the symptoms of brain tumors, as well as how they are diagnosed and treated.

The brain and spinal cord form the central nervous system (CNS). That is why brain and spine tumors are also known as CNS tumors.[1,9]

Nerves in the spinal cord send messages through pathways between the brain and the rest of the body.[1,11] These messages tell our muscles how and when to move, forward information gathered by our five senses, and control how our body functions.[11] Our brain also manages how we think and feel. The CNS is the core of our existence, giving meaning to things that happen in the world around us.

The CNS controls:

- Personality: thoughts, memory, intelligence, speech, understanding, and emotions
- Senses: sight, smell, hearing, taste, and touch
- Basic body functions: respiratory rate, heartbeat, and blood pressure
- Movement: standing, walking, balance, and coordination



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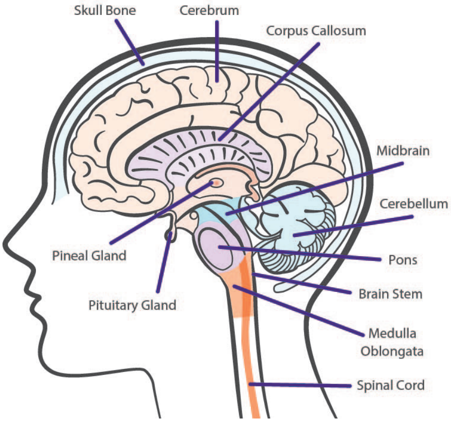
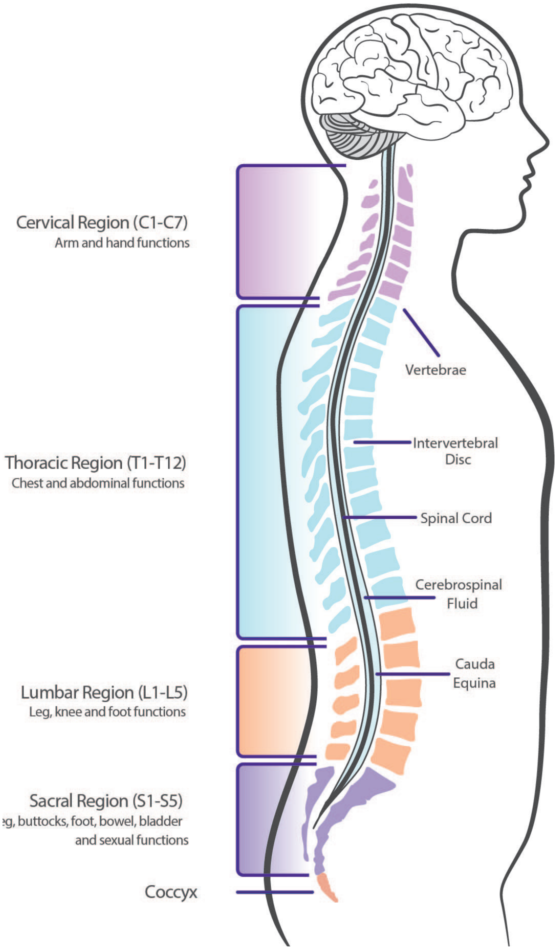


CENTRAL NERVOUS SYSTEM



Major Parts of the Brain

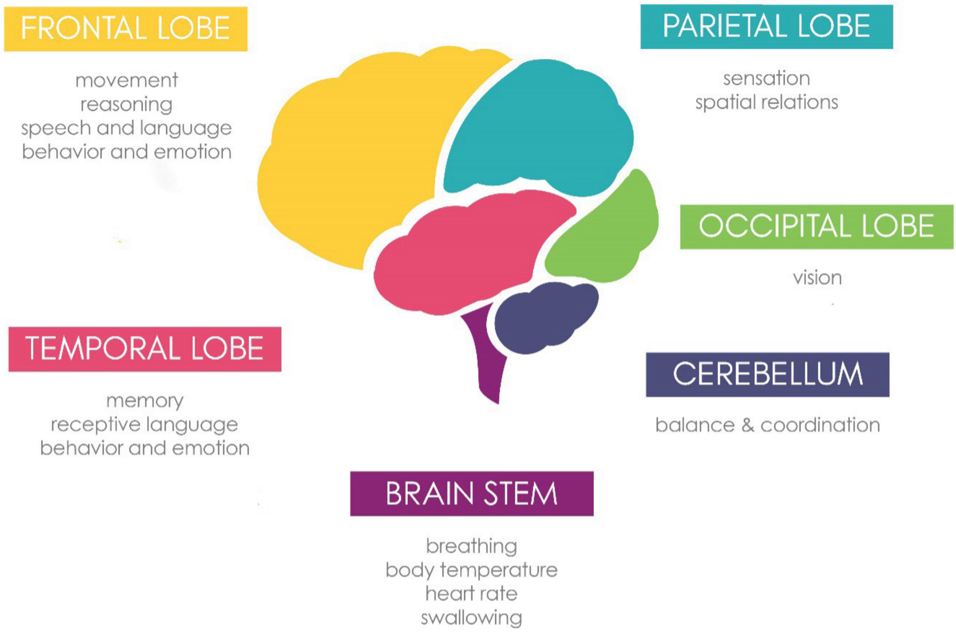
There are three major parts of the brain.

- The **cerebrum** uses information from our senses to tell the body how to respond. It controls thinking, learning, emotions, speech, and movement.
- The **cerebellum** controls balance for standing and walking, and other movements.
- The **brain stem** connects the brain with the spinal cord and controls basic body functions such as breathing, heartbeat, swallowing and blood pressure.[9,11,70]

Lobes of the Brain

The brain is further divided into broad regions known as lobes.[11] Different lobes control different functions (see the diagram below). As an example, the frontal lobe of the brain controls thinking, reasoning, and speech,[9,11] while the temporal lobe controls memory, comprehension and hearing.

When brain tissue is damaged by a tumor, it interferes with the messages being sent between the brain and the body.[11] That means a brain tumor in the frontal lobe can cause changes in thought, reasoning, behavior, speech, and/or personality.[2,8] A brain tumor in the temporal lobe may cause problems with memory and/or comprehension[8,11] But because the lobes are connected to each other and work together,[11] it is possible that the tumor could impact a function of the brain beyond where the tumor is located.



Healthcare Team

Your Healthcare Team

Many different types of doctors, nurses, and other providers will likely comprise your healthcare team. Don't be afraid to ask the people on your team what their role is, what kind of training they've had, and what part of your care or treatment they'll be providing. Knowing how your care team works and how they communicate with each other will help you and your loved ones understand who can help with certain problems that may come up. The following is a list of some of the medical professionals you may encounter:

- **Neurosurgeon/neurosurgical oncologist**: A surgeon who specializes in CNS surgery.
- **Neuro-oncologist:** A doctor who specializes in medical (non-surgical) treatment of patients with CNS tumors.
- **Medical oncologist**: A doctor who specializes in medical (non-surgical) treatment of patients with cancers or tumors of the body.
- **Radiation oncologist:** A doctor who specializes in using radiation to treat patients with CNS tumors or tumors of the body.
- **Primary care physician**: A doctor who can help find specialists and coordinate overall care.
- **Neuro-oncology nurse**: A registered nurse who specializes in supporting and educating brain tumor patients.
- **Nurse practitioner or physician assistant**: A healthcare professional with an advanced degree who can either be a primary provider or may work alongside a doctor to develop a treatment plan.
- **Medical assistant**: A medical professional who provides basic clinical services, often in outpatient settings.
- **Social worker**: A provider who offers services such as counseling, assistance in making medical decisions, coordinating at-home care, finding financial resources, offering resources and referrals for a mental health provider or chaplain, and more.
- **Nurse navigator**: A nurse who assists with appointment management, insurance, disease education, information on symptoms and side effects, and finding resources, among other tasks. These nurses often specialize in the specific diagnosis for which they are providing navigation services.

Related Specialists

In addition to the main healthcare team, you may also see additional specialists, depending on your specific diagnosis, symptoms, and needs. They may include:

- **Neuropathologist**: A pathologist who analyzes brain tumor tissue removed during surgery and then prepares a pathology report, which helps determine treatment options.
- **Neuropsychologist**: A psychologist who helps assess and provide strategies for patients who are experiencing cognitive, behavioral, and emotional symptoms/side effects.
- **Psychiatrist**: A doctor who diagnoses and treats mood and emotional issues that may arise from the brain tumor or its treatment.
- **Neuroradiologist**: A radiologist with special training in reading images of the brain and CNS.
- **Neurologist**: A doctor who specializes in treating patients with neurologic symptoms and disorders.
- **Rehabilitative specialist**: An occupational, physical, or speech therapist who can help improve a patient's strength, mobility, memory, or communication.
- **Endocrinologist**: A specialist who may be consulted if the brain tumor or treatment affects one of the patient's endocrine organs, such as the pituitary gland.
- **Child life specialist**: A healthcare professional who works to reduce anxiety and distress for children during their hospital experience.
- **Dietitian/nutritionist**: A healthcare professional who can help identify healthy eating habits and supplements that can help minimize symptoms/side effects.
- **Clinical research nurse/coordinator**: A healthcare professional who specializes in research and can help patients navigate clinical trials.

Questions to Ask Your Doctor

Primary Brain Tumors

Diagnosis

- What can you tell me about my brain tumor type?
- Is my tumor non-malignant (benign) or malignant (cancerous)?
- How do you expect my brain tumor to progress?

- What is my prognosis with and without treatment?
- How likely is a recurrence?

Treatment

- What are my treatment options? What are the goals of treatment?
- What are the risks and benefits of the recommended treatment?
- Can treatment wait?
- How long do I have to make decisions about my course of treatment?
- Are alternative treatment options available?
- How do you determine if the treatment is effective? What follow-up tests do you recommend?
- What are the common side effects associated with the recommended treatment?
- What are the potential long-term effects of each treatment?
- How did you decide on these treatment options?
- What is the expected time frame of my treatment?
- Can I work and/or resume activities, including driving, while in treatment?

Fertility Preservation

- Will these treatment options impact my fertility?
- How long do I have to consider my fertility preservation options?
- Will preserving my fertility require delaying starting treatment?

Surgery

- Where is the tumor located and what is its size?
- Is my tumor operable?
- What are the risks of surgery? Could surgery impact my memory, my ability to think, my movement or my speech?
- How can I ensure enough of the tumor is removed so that I have the option to get molecular testing?
- What happens after surgery?
- Does the hospital/medical center offer molecular testing?
- When is the optimal time to have molecular testing?
- If your hospital/medical center does not provide molecular testing, where do you refer patients who request this testing?

Clinical Trials

- Are clinical trials a treatment option?
- Are any clinical trials available now? When would I be eligible to participate?
- Where can I find information about clinical trials?
- What are the potential risks and benefits of participating in a clinical trial?
- How will the clinical trial doctors coordinate with you while I participate in a clinical study?

Your Healthcare Team

- How many brain tumor patients with my tumor type do you treat annually?
- What other specialists will be part of my healthcare team? (e.g., neuro-oncologist, neurosurgeon, radiation oncologist, nurse, nutritionist, etc.)
- What is the role of each member of my healthcare team?
- How will members of my healthcare team communicate with you?
- If I am hospitalized, will you be my doctor?
- How frequently will I have appointments and how long will they last?

Support Services

- Where can I get more information about my diagnosis?
- What support services are available to me and my family and/or caregiver?
- How do I talk to my employer about my diagnosis?
- How do I talk to my family and friends about my diagnosis?

Lifestyle

- Do I need to change my diet?
- Do I need to make any lifestyle changes?
- How might this affect my quality of life and how long will these effects last?

Selecting Your Healthcare Team

- Does the healthcare team seem interested in your questions?
- Does the healthcare team spend enough time with you and address your concerns?
- Do you feel comfortable with the doctor’s recommendations?
- Is the doctor open to you seeking a second opinion?
- Do you feel like you have a say in your treatment plan?

Metastatic Brain Tumors

Diagnosis

- What can you tell me about my brain tumor type?
- Was molecular testing conducted to ensure the accuracy of tumor type?
- What is my prognosis, with and without treatment?
- How many patients with my tumor type do you treat annually?

Treatment

- What are my treatment options?
- What are the goals of treatment?
- Can treatment wait?
- If radiation is recommended, what is the difference between Whole Brain Radiation Therapy (WBRT), Intensity-Modulated Radiation Therapy (IMRT) and Stereotactic Radiosurgery (SRS)?
- Considering the cognitive side effects associated with WBRT would SRS be better suited for me?
- Is SRS available at this treatment center? If not, is SRS available in the area?
- If WBRT is the best treatment, how do you recommend preserving my cognitive functioning? Is hippocampal avoidance possible?
- What are the risks and benefits of each treatment?
- What are common treatment side effects?
- How will treatment affect my daily activities?
- How do you determine if the treatment is effective?
- What follow-up tests do you recommend?
- What are the possible long-term effects of each treatment?
- How do you expect my brain tumor to progress?
- Will it spread or come back after treatment? Are there alternative treatment options?
- Would a clinical trial be right for me?
- Do you recommend getting a second opinion?
- Whom would you recommend I consult?

Fertility Preservation

- Will these treatment options impact my fertility?
- How long do I have to consider my fertility preservation options?
- Will preserving my fertility require delaying starting treatment?

Support Services

- What survivorship services are available to me and/or my family?

Questions to Ask During a Second Opinion

- What is your doctor's experience with treating brain tumors?
- Is your diagnosis the same or different?
- What treatment(s) do you recommend for it?
- Are there other viable treatments I should consider?
- Are there any clinical trials I should consider?
- Are there any additional tests I should have?
- What happens if I wait or don't receive the treatment(s)?
- Are there side effects associated with the treatment option(s)?
- Are there any other risks associated with the treatment option(s)?
- How long is the recovery period for each treatment option?
- What are the expected outcomes of each treatment option?
- How much will the treatment cost? Is it covered by insurance?

Questions to Ask Regarding Insurance Coverage

- What type of insurance plan do I have?
- What percentage of my bill will be paid by insurance?
- Does my policy have an out-of-pocket maximum?
- Is my doctor in network? Do I need a referral from my primary care physician, or will I need authorization from my insurance?
- Does my insurance cover a second opinion?
- Do I need to obtain pre-authorization for hospitalization or treatment?

- Does my insurance plan cover physician costs, virtual care, as well as inpatient and outpatient hospital services?
- Does my insurance plan cover prescription medications or chemotherapy medications?
- Will my insurance cover my participation in a clinical trial if I choose it?
- What, if any, are my co-payments?
- If I choose to go out-of-network, what percentage of my bill will be paid by insurance? What is the amount of my deductible?
- Does my insurance plan offer any additional coverage through special networks for treating medical conditions such as cancer?
- If my out-of-pocket expenses reach a certain amount, will my insurance reimburse me at 100%?
- How does the insurance company handle disputes over claims?

AMERICAN BRAIN TUMOR ASSOCIATION
INFORMATION, RESOURCES AND SUPPORT

Educational brochures and additional resources are available on our website, or some can be requested in hard copy format for free by calling the ABTA. Most brochures are available in Spanish.

GENERAL INFORMATION

About Brain Tumors: A Primer for Patients and Caregivers
Brain Tumor Dictionary
Brain Tumors: A Handbook for the Newly Diagnosed
Caregiver Handbook

TUMOR TYPES

Ependymoma
Glioblastoma & High-Grade Astrocytoma
Medulloblastoma
Meningioma
Metastatic
Oligodendroglioma
Pituitary

TREATMENT

Chemotherapy
Clinical Trials
Conventional Radiation
Proton Therapy
Stereotactic Radiosurgery
Steroids
Surgery

ADDITIONAL RESOURCES

Neuropsychiatric Symptoms
Questions to Ask Your Doctor – Primary Brain Tumors
Questions to Ask Your Doctor – Metastatic Brain Tumors
Seizure First Aid

AMERICAN BRAIN TUMOR ASSOCIATION
INFORMATION, RESOURCES AND SUPPORT

INFORMATION

ABTA WEBSITE | ABTA.ORG

Offers more than 200 pages of information, programs, support services and resources, including: brain tumor treatment center and support group locators, caregiver resources, financial assistance, research updates and tumor type and treatment information across all ages and tumor types.

EDUCATION & SUPPORT

ABTA Educational Meetings & Webinars

In-person and virtual educational meetings led by nationally recognized medical professionals.

ABTA Patient & Caregiver Mentor Support Program

Connect with a trained patient or caregiver mentor to help navigate a brain tumor diagnosis.

ABTA Connections Support Community

An online support and discussion community of more than 35,000 members.

ABTA CareLine

Connect with a CareLine staff member for personalized information and resources. Call 800-886-ABTA (2282) or email info@abta.org.

ABTA Financial Assistance Program, Glenn Garcelon Fund

Offers limited financial assistance for patients diagnosed with a primary benign or malignant brain or spine tumors.

GET INVOLVED

- Join an ABTA fundraising event or volunteer.
- Donate by visiting abta.org/donate.
- Share your story.

CONTACT THE ABTA

CareLine: 800-886-ABTA (2282)
Email: info@abta.org
Website: abta.org

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